



Second Wind

NEWSLETTER

NOVEMBER-DECEMBER 2002

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, or relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.



Happy Holidays! Are you in the midst of holiday preparations, struggling to keep up to the standards that you *think* you kept many years ago? Such stress is enough to take the pleasure out of this “happy season” for many of us. If “*stressed*” is the word that best describes your life these days may we offer a suggestion? Pull up your favorite chair, elevate your feet and *relax* for a few minutes while you get ready to read this month’s newsletter. Take a nice slow, deep breath *in*, and then breathe *out* slowly through pursed lips. Be sure to drop those tense shoulders. Put *yourself* first on that gift list, making your own sense

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of peace, relaxation and quiet your number one priority.

While you were busy buying gifts to put under that tree, many of you also remembered to make a gift to PERF, which helps us continue in our efforts to help others with respiratory disease. Our grateful thanks go to:

Dr. Vernon Read, and Freda Standeford for their donations for research. Gladys Mollison, Sharon & Vince Foster, and an anonymous donation in memory of Walter Hirschland, for the Chair in the Rehabilitative Sciences. Shirley Brunmeir made her donation to the Chair in memory of her son, Christopher Tinnon,

Other memorial donations were from Tom Burrows for Doris, Bev Purdum for Bill, Rodney Norris for Penny, Peter Williams for his son, Keith, Jean Krenicki for Lillian Fay, Pat Ternstrom in memory of Staci, Jeanne Barton in memory of Dick, James Lynch in memory of his wife, Mary, Georgia Cline in memory Andy, and Barbara White in memory of Harry Holcomb, Chuck Gaynor, George Richey and Lil Faye, Nancy Moore in memory of Glen, Jeanne Rife in memory of John, as well as Genny Schaniel who made her donation in honor of her “3 HH sisters.” (Thanks, Gen!)

*Mary spends special thanks to Dave Nelson and Linda Burns for their very generous donation to PERF in her honor. She also sends humble thanks to Denise Giambalvo, RN, MN, Marge Spitzel, RN, MN, Billie Gaynor and C.Alopari for their donations, also made in her honor. **YYY***

Very special thanks are also in order for Alvin Grancell, Dr. Tom Petty, Dr. & Mrs. Rich Casaburi, Jeanne Rife, Pete Pettler, Dr. Brian Tiep, Mary Burns, Alvin & Jean Hughes, and Barbara Borak, who not only donate their time to PERF, as members of the Board of Directors, but who also make generous financial contributions. They believe in PERF!

Thanks also to Audrey Samardich, Dick & Ann Wentink, Rose Shields, Priscilla Mills, Warren Mittelholz, Lloyde Livingstone, Peggy Dupont, G.

Salvador, Irene Peterson, Mickee Heumann, Alrene Geer, John Hill, Wayne Chinen, Virginia Brown, Sharon Foster, Buckley Walsh, Ann Little, Don Murphy, Yolanda Weiss, Betty Hoffmeier, Leslie Fortin, Shelby Webb, Robert Zerfing. Dwain Essig, Elizabeth Krantz, Ted & Ginny Von Goerlitz, Lois Abrams, John Reifel, Whitney Sponsler, Francis Scilley, Ron & Marion Littlefair, Linda Deighna, Phyllis Riker, Paul Selecky, MD, Gerald Sandman, Dale & Doris Thompson, Marilyn Holocher and Joyce Strickland. And very, very special thanks to Reta Long!



The **GOLD Program** (Global Initiative for Chronic Obstructive Lung Disease) conducted the **first annual World COPD Day, with the theme “Raising COPD Awareness Worldwide” on November 20th, 2002.** This was the start of an ongoing campaign to make the public more aware of COPD, and physicians more aware of diagnostic tools. GOLD is focusing on the awareness of COPD because worldwide data suggest that an astonishing number of people, including health care professionals, are unfamiliar with COPD. Yet, COPD is now the 4th leading cause of death worldwide, and is a staggering burden to the health care community. The cost of care for COPD is enormous, yet early detection, and smoking cessation can prevent the ravages of the long-term impact of lung destruction caused by COPD.

On World COPD Day, in over 72 countries, the GOLD Program worked with national societies, physicians, patient groups, and government officials to develop programs to bring awareness to COPD. Media campaigns, public service announcements, press briefings, and local events were among the activities planned. Twenty-three state governors declared November **COPD Month**. Did *your* state take part in acknowledging this serious health problem?

Visit the GOLD Website at www.goldcopd.com for information on how you can join the yearlong campaign to “Raise COPD Awareness Worldwide.”

The American Association for Respiratory Care and other members of the U.S. COPD Coalition were rewarded with a presidential message regarding COPD in their efforts to have November named as **COPD Awareness Month**.

In part that letter reads: "I commend the organizations of the United States Chronic Obstructive Pulmonary Disease Coalition for your efforts to increase awareness of COPD and I applaud your work to advance care for those affected by this disease." You may view the entire message on the US COPD Coalition website at http://www.uscopd.com/index_aware.html

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Wes Shull shared with us this letter he received in response to a request for an update of the **FORTE** research. **As many of you know, this research is aimed at determining whether a way can be found to stimulate the lung to grow new tissue and improve its function.** We know that you *also* will be interested. Thanks, Wes.

This is in response to your inquiry about the results of the National Heart, Lung, and Blood Institute funded study "Feasibility of Retinoids in the Treatment of Emphysema."

The Feasibility of Retinoids in the Treatment of Emphysema (FORTE) is a multi center program of preliminary studies to determine whether conducting a larger, controlled, clinical trial on the efficacy of retinoic acid therapy in the management of emphysema is possible and indicated. FORTE finished recruiting participants on July 1, 2002. The last enrolled participants will be followed until May 2003, after which the investigators will collate, analyze, and interpret the data. The investigators expect to release results early in 2004. No interim results have been released.

Because this was designed as a feasibility study, it is possible that the results will be inconclusive as to the risk and benefit of retinoids in emphysema. What we hope to learn from FORTE includes questions like: which retinoid, and what dose should be used, if a larger, definitive study were conducted? How should the retinoid be given? What measurement should be followed to look for an effect? Is retinoid too toxic in patients with emphysema to conduct a larger study? What kinds of patients with emphysema should be studied? How many patients with emphysema would be needed to conduct a *meaningful* study, that is a study powerful enough so that the investigators can be sure the results have

general applicability? These are the kinds of questions that the FORTE investigators expect to address at the end of the study.

Thank you for your interest in this program.

Gail G Weinmann, MD
Director, ABDP, MSC 7952
DLD, NHLBI, NIH



While our friends in Scandinavia were shoveling snow, and friends in the Northeast were struggling with ice storms, we had our own problems here in Southern California: Santa Ana winds with hot, sunny, dry weather in the nineties. You don't feel sorry for us? Well, I can see why, but the operative word here is *dry*. The humidity can go as low as 10%. This is a temporary condition, so why should we talk about it in a newsletter that goes around the world? *Even if you don't live in a warm desert climate, you too may be having problems associated with dry air as you heat your homes to escape the cold.* Let's talk about solving some of the problems our patients in Southern California had with the dry air to see if we can help you also. When you turn on your furnaces, you may also turn the inside of your house into a warm, *dry* environment. Why is that a problem? I'll bet many of *you* could answer that. Do you ever get a dry tickle in your throat causing an irritated cough? Do you sneeze a lot even though you don't have a cold? Do you get nosebleeds? Dry mucus membranes may cause these symptoms, a warning that your need to increase the humidity in the air.

What happens if you don't? You may become more susceptible to respiratory infections and, a more immediate problem in addition to those already mentioned, find that your sputum becomes thick, and difficult to expectorate, maybe to the point where you feel as if you are choking or can't get your breath.

Needless to say, you should *call your doctor* if you are having increased difficulties with your breathing or sputum. But if your physician finds nothing really wrong, what can you do to help yourself? There are various techniques.

Drink more fluids! Take frequent sips during the day. You don't think you ever perspire and so don't need as much fluid as other people do? Perhaps, but be aware of something called "insensible perspiration". That is just a fancy way of saying that in dry air your perspiration evaporates so quickly that you are not aware of it. A better way to evaluate your need for more fluids is to be aware of the color of your urine. It should be very pale yellow. If it is a darker yellow that usually means your urine is concentrated and you need more fluids. Be aware that when you first void after taking a pill that contains a Vitamin B you may have dark yellow urine. Hepatitis and liver disease can also cause dark yellow urine but most of you need not be concerned by that uncommon cause.

How much fluid should you drink a day? While we often hear that 8 glasses should be consumed, remember that this does not hold true if you are on diuretics (water pills) or have a heart problem. Ask your physician for guidance on this. Also, all of your fluid intake doesn't come from water. When you think about increasing fluids, remember that anything that is a fluid at room temperature is *also* considered a fluid. That means foods like ice cream, and jello. Don't forget soups, and remember that all fruit (that isn't dried) contains a lot of fluid. These things can all add up. Alcoholic beverages are considered diuretics, that is, causing a *loss* of fluids in the body. Drinking extra beer is *not* a good solution for increasing your fluid intake!

If your sputum is still very thick, even though you have increased your fluid intake, remember that sitting in a steaming bathtub or shower and inhaling that moist air will thin out your secretions. That is why sometimes people who produce large amounts of sputum may feel as if they are choking when they get into a humid atmosphere. The increased moisture in the air makes their sputum expand from the moisture inhaled with the air. While this may be a problem for people with thin sputum, it is exactly what we want to happen if your sputum is too thick to expectorate, to cough up.

Suppose you are too unsteady to get into a tub or shower. What else can you do? Remember those old-fashioned croup tents? You can improvise your own by boiling water in a large pan, and inhaling the steam. But *be careful*. Be sure to turn the handle away from you so that you don't accidentally spill that boiling water and burn yourself!

Another suggestion is to have a cup of steaming water, tea or coffee. Inhale the steam as you sip from the cup. This works well when you are away from home or up in a plane, where humidity can go as low as 4%. Tea and coffee also contain theophylline-like ingredients that may help open your airways.

After inhaling the steam for 10 minutes or so, you might also consider postural drainage and percussion an hour before you go to bed. Usually we only recommend postural drainage for folks producing large amounts of sputum, such as ½ cup or more a day. However, if you wake up coughing in the middle of the night with sputum, postural drainage might help clear your airways *before* going to bed and help you sleep better.

Postural drainage means lying down on your belly and, with the aid of pillows under your hips or waist, tilting *down* your upper body (and lungs) so that gravity helps get your secretions out. Even being almost flat, as you are at night while sleeping, helps gravity compared to

your upright position all day. That is one reason why you may cough up secretions during the night. Try lying on one side or the other for 20 minutes or so as you watch TV.

While you then may produce secretions, it may take another 30 minutes or so, which is a good reason for not doing this drainage immediately before going to bed. If you need to cough while still lying down, it is easier to sit up to do so.

Are you on oxygen? Percolating your oxygen through a humidifier bottle, as is done in the hospital, also helps humidify your air. These bottles look much like a Mason jar. In the early days of home oxygen, all oxygen came with a humidifier. However, studies found that patients did not always keep these bottles clean, turning them into a source of infection. Currently, you will get a humidifier bottle if you use 3 or 4 liters of oxygen per minute. If you use less oxygen, but suffer from dry air, you may request such a unit from your oxygen supplier. Sometimes these bottles will come as sealed units, replaced by your oxygen company as necessary. In some locations, *you* will have to assume responsibility for these humidifiers. You will be instructed to keep the bottles three-quarters filled with sterile or distilled water and given cleaning instructions. They probably will give you several bottles so that you can thoroughly clean and rotate the bottles on a regular basis, rather than just continuing to refill them as

the water level goes down. Hot soapy water, rinsing thoroughly, and air-drying will work if you don't have a dishwasher.

Do you have any additional tips for helping other lung-challenged readers survive the winter? Send them in and we will share them with others in the next issue.

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Wayne asks, “*Why do people with COPD have more trouble breathing with cold weather?*” One of the detailed answers is above. The air tends to be drier, or our heating of the air *makes* it drier. Cold air can also cause bronchospasm (narrowing of the air passages), especially when there is also a strong wind to contend with. You can compensate for this by wearing a ski mask, covering your nose and mouth with a scarf, or turning your back to the wind.

Come out of your car slowly, to compensate for sudden temperature change, which can also cause bronchospasm. That is, open the door for a few seconds before suddenly getting out of the car.

Really cold air can actually freeze the hairs in your nose! Can you imagine what it could do to the fragile tissue in your lungs, which are one-sixtieth the thickness of a cobweb? Be reassured. Your respiratory system has a much more efficient temperature control mechanism than anything that has been designed by man. Whether the air you breathe in is 160 degrees

above zero and almost hot enough to fry eggs, or 80 degrees below zero and freezing everything else in sight, from the time this air enters your nose, until the time it enters your lungs, that air has become body temperature! For those of you who are looking for miracles look no further. This is one that leaves me breathless when I consider the wonder of it.

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Do you think that *Christians* are the only ones who can get caught up in the Christmas spirit? Well, think again. Our Japanese friends happily tell us that, while they are good Buddhists, in the month of December they join us in traditional Christmas celebrations. **Tetsuji Watenabe**, of the Teijin Company sent us a unique Christmas card of a large Buddha surrounded by miniature Santa Clauses busily sweeping off snow. And inside, was a generous check for PERF in honor of Mary. With typical modesty, he wrote, *"I hope my small donation will be somewhat helpful for COPD treatment. The amount I sent is small but it is "a poor one's small candle". What is "a poor one's small candle"? In the old days, Buddha visited a town in India to give a religious speech. Lots of rich people gathered around him to listen, holding big candles to light up this holy place. There came in a very poor old lady with a very small candle in her hand. People laughed at her small candle, which she had sold her hair to get. Buddha began his religious talk when suddenly a big*

wind arose, blowing out all the candles but that of the old lady. Buddha said, "Look at her candle, everyone. The old lady's candle is small but its light glows large with faith." Tetsuji described his donation as a "small candle". Your "small candle", Tetsuji, along with all the others we credited earlier, is helping to provide the light for a brighter future for those with respiratory disease. Thank you all! ♥♥♥

And speaking of a brighter future, please remember the **Rehabilitation Clinical Trials Center at Harbor-UCLA in Torrance, CA**. It has *many* ongoing studies, for men and women. If you live in driving distance, give them a call at **(310) 222-8276** and learn more about what might be of special interest to you.

There is much more information, news and pictures, to share with you but it will have to wait until next month. Your editor took her own advice. She reduced *her* stress by cutting back to one combined November-December newsletter! Be sure to read the January newsletter for more information about the treatment of COPD in Norway, as well as the hottest topics here in the United States. If you have any particular requests, call, write or e-mail and we will try to cover that information.

As we end the year of 2002, we wish Happy Holidays to all of you from all of us. May you be blessed with a healthy and happy New Year!

